

## *Diabetes Research and Training Centers— Making a Difference in Diabetes Care*

Grace Hill Neighborhood Health Centers, Inc. uses a model to evaluate its diabetes care that sounds like it is straight out of corporate America: Plan-Do-Study-Act. But its clients definitely are not corporate. The six clinics Grace Hill runs serve mainly poor African Americans in St. Louis, MO. “Eighty-six percent of our patients are uninsured,” says Veronica Richardson, Grace Hill’s director of chronic care management. “People we work with are sometimes just a paycheck away from being homeless,” and some live in households where one income stretches to cover three generations.

Grace Hill is part of a 70-center network that gets help from the University of Chicago’s Diabetes Research and Training Center (DRTC). “We work with them on quality improvement issues,” says Dr. Marshall Chin, a researcher at the Chicago DRTC.

Like the five other NIDDK-funded DRTCs, the Chicago group does basic and clinical research and looks for ways to close the gap between what researchers know is good care and how patients are actually treated. Their Prevention and Control Divisions (formerly known as Demonstration and Education Divisions) “translate” clinical discoveries into clinical practice through education programs, professional training, and community outreach; they study the barriers that block ideal diabetes care, and they help providers assess their programs.

Most members of the network Chin works with are “safety net” providers supported by the Bureau of Primary Health Care, a federal agency whose mission is to improve the health of underserved populations. These providers work in resource-constrained settings, so delivering good diabetes care is challenging, says Chin. “If we can treat successfully in these settings, then we can probably change care in other settings.”

“At Grace Hill, there’s excellent leadership and a committed staff willing to try many interventions,” adds Chin. “Because the centers are small and non-bureaucratic, they have the attitude and values that allow them to change quickly.”

He says that the Plan-Do-Study-Act (PDSA) model is a way to try new interventions and to move on quickly, if they don’t work. “The model provides a framework, then the clinics can get creative.”

Grace Hill uses the model when it evaluates patient materials and management changes. They use several small cycles of testing before deciding to print large quantities of patient materials. For instance, they take steps as basic as checking the readability and cultural sensitivity of patient information with a few people. “We don’t want thousands of copies of something to end up in the basement because they couldn’t be used,” says Richardson.

One of Grace Hill’s more successful changes, the “group cluster clinic,” was developed with PDSA. The cluster visit is a sort of one-stop shopping: patients come in and see all relevant health care providers at once. “It’s an idea we got from another group that worked with all insured folks, but we weren’t sure it would work for us,” says Richardson. But they wanted to do something about the high no-show rate—it was more than 50 percent—that occurred when patients were scheduled for many separate visits.

The first attempts failed. The first diabetes cluster clinic was opened a few days before Christmas on the coldest day of the year. The staff learned not to schedule near a major holiday. Initially, they offered the clinic to groups that included homeless and non-homeless people. But the tensions between the two groups and their different needs ended that idea.

They also tried to do the cluster clinic for their homeless clients at the beginning of the month. But when that did not work well, “we moved it to the middle of the month,” says Richardson.

The way the group cluster visit works now, the patients with diabetes come in first thing in the morning, go to the lab, get a healthy breakfast at the clinic, and then have a group education and support session. The nutritionist may talk, and people discuss what has worked in their own management of the disease.

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Meanwhile, explains Richardson, the staff looks at the records and decides which patients have to see which provider. The patients don't see every provider during every visit, but there's a general doctor, an eye doctor, a foot doctor, a social worker, and a health educator, says Richardson.

Grace Hill's patient registry is sophisticated enough to track when patients need to come in and for what tests, and it lets the providers know when someone has skipped a particular exam. From the registry, the staff can create lists for the health care coaches, neighborhood people hired by Grace Hill who meet one-on-one with clients to coax them into improving their care.

## **Doing It All**

Translation work since 1977 has shown the diabetes community just how broad the care issues are, says Dr. Edwin Fisher, a psychologist at Washington University's DRTC in St. Louis. "Twenty-five years ago, it was assumed that good doctors, good nurses, and good curricula could solve the problem of diabetes. Now, we know that it involves the community, the public health people, psychologists, et cetera."

"We've done a great job at developing materials, but we're still not good at changing behaviors," adds Chin. "We have to do it all."

Doing it all means educating patient and practitioners, involving the greater community (see story, page 30), and even changing how the medical system manages patients. Over the years, the DRTCs have done numerous studies that tackle issues in each of these areas.

## **Helping the Patient**

The DRTCs have developed patient education programs that address issues ranging from cultural relevance to motivation. For instance, the University of Chicago developed the "Pathways Lifestyle Modification Program for African American Women," a successful lay educator program designed for inner city African American churches, and the University of Michigan created "Living With Diabetes: Challenges in the African American Community."

Dr. Roland G. Hiss, chief of the Prevention and

Control Division of the University of Michigan DRTC, thinks that a patient empowerment approach developed at Michigan "is the most important thing we've done in the nonbiomedical field." The approach is used in diabetes care in many places in the United States, and it is attracting interest in other countries, including Mexico, the United Kingdom, Germany, and Japan.

The underlying concept in patient empowerment is goal clarification, explains Dr. Robert Anderson, a Michigan DRTC researcher. The idea is to help patients find the first small step they want to take in their care and to explore their feelings about what will happen if they don't make changes.

Until a patient internalizes that 'I want to live a healthier life,' 'I want to be there for my grandchildren,' or some similar message, "then nothing happens. Motivation is a personal thing, and it can't be superimposed from the outside," says Anderson.

"We have to help patients discover their motivations," adds Anderson. He and his Michigan colleague Martha Funnell turned the approach into a book called *The Art of Empowerment*, which is published by the American Diabetes Association (ADA). They also have taken strategies from the book and tailored them for urban African Americans.

As they developed the empowerment principles, Anderson says the researchers wanted to make sure patients understood the clinical implications and consequences of their health choices and found ways to mesh their diabetes care and their lives. "We also help them discover whether their decisions are supporting their goals."

On the patient education side, there has been a greater recognition that people do what makes sense for their lives, says Fisher, so successful patient education has to emphasize flexibility and choice.

Fisher says years of behavioral study show that people who are more advantaged are better able to change their behaviors, probably because they have fewer barriers to care. Researchers know behavioral changes are more likely to occur in a person if they hear about its necessity from several sources. Also, the longer programs to support behavior change are maintained,

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the longer those changes will persist, he adds. "Chronic behavior, just like chronic disease, needs chronic care."

Another determinant of long-term behavior change is encouragement and support. "But, as much as we know support is tremendously important in health, we don't know very much about what is supportive in what circumstances," says Fisher.

The Diabetes Control and Complications Trial, a 10-year, multi-center clinical trial that ended in 1993, had shed some light on motivation. DRTC researchers at Washington University found that patients who participated in the intensive arm of the study reported that they had received more non-directive support than directive support. (The researchers describe non-directive support as cooperating without "taking over" and accepting people's feelings and choices, and directive support as taking control and telling people what to choose or feel.) That patients reported more non-directive support from staff was "a bit of a surprise since the highly detailed and technical demands of the DCCT Intensive Treatment might have made it reasonable for staff to provide a lot of directive support," says Fisher, who adds that earlier studies show that non-directive support is associated with better metabolic control and quality of life. The DRTCs at the University of Chicago, Albert Einstein College of Medicine, Indiana University, and Washington University have begun studying the two forms of support to evaluate how they may help patients adhere to protocols in future studies.

One support that has greatly helped patients is the telephone. Dr. Elizabeth Walker, director of the Prevention and Control Division of the DRTC at Albert Einstein College of Medicine in the Bronx, reported a doubling of the screening rate for retinopathy among African Americans in a study using a telephone intervention. During the conversations between interviewer and patient, the interviewers would help patients find and overcome their personal barriers to screening. Perceived lack of time and acute health care problems that took precedence over preventative care were among the reported barriers. The researchers are now evaluating the cost effectiveness of the phone interven-

tion in English and Spanish.

Dr. Judith Wylie-Rosett of Einstein's Prevention and Control Division has developed and evaluated strategies for providing weight control services in community settings. Among the strategies are a workbook, now published by ADA, and a computer program. Both help people prioritize weight loss strategies that might be helpful to them. Wylie-Rosett hopes to take further advantage of technology by using the Internet. One idea is to use cyber cafes in schools and other sites to address the rise in youth obesity and diabetes.

Supporting patients requires understanding their specific needs, according to Dr. Loretta Heuer, diabetes coordinator of Migrant Health Services, Inc, in Moorhead, MN. She and her colleagues serve Hispanic workers who move to rural Minnesota and North Dakota to work the farms every summer. When their labor is done, they go home to Texas. Of the 6,000 patients served, approximately 400 have diabetes, and the most common medical reason their patients visit is for diabetes care, says Heuer.

To stay on top of patient care, the nurse-managed clinics in Minnesota remain in contact with clinics that serve the migrant workers back home in Texas. They have also trained members of the community to be lay educators. "When they go back to Texas, the lay educators restart support groups," says Heuer.

The group collaborates with the DRTC at the University of Chicago. "We provide them with data on how to make patient visits more effective," says Heuer.

The program for the migrants runs on federally funded vouchers that pay for medical care such as visits to physicians and dentists, laboratory tests, x-rays, and medications. The patients receive the voucher and referral from Migrant Health Services as needed, says Heuer. "The vouchers make it possible to provide good care."

Because it is a voucher program, the nurses and nurse practitioners can spend enough time with patients. It's not unusual for them to take an hour or more during a visit, which gives the patients enough time to start building trust, says Heuer. "It's a culture where it would be offensive to have a short visit."

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The building of respectful relationships can only improve care, according to Heuer, who adds that she and her colleagues are seeing drops in hemoglobin A1c (A1c) levels in their patient population. “It makes you feel like you are not running upstream.”

### Teaching Providers

Several DRTC projects have worked to improve the ways providers deliver diabetes care. Materials have been developed for dietitians, doctors, diabetes educators, and other members of the diabetes care team.

For instance, at Einstein, Wylie-Rosett has collaborated to develop the WAVE interview, which helps time-pressured physicians make faster nutrition assessments of patients. WAVE stands for weight, activity, variety (varying time of day for carbohydrates), and excess (looking at excessive behaviors around carbohydrate consumption). “We’ve used WAVE to train medical students to integrate a five-minute screening nutrition evaluation into the care of women with gestational diabetes,” says Wylie-Rosett. “Physicians who address nutrition are more likely to refer patients for needed medical nutrition therapy.”

One focus of the Indiana University DRTC researchers involves training future doctors and established practitioners. In one project, they worked with second year medical students who had never touched a patient. The idea was to teach them to make better decisions about diabetes care. The students would receive the patients’ charts and decide what to do. Then they would watch videos with real patients and experienced doctors doing the examination. Finally, one of the doctors shown in the video debriefed the students. “We put them into a clinical simulation and made them get smarter,” says Dr. David Marrero at Indiana University’s DRTC. “They came up with good treatment ideas, and their performance was comparable to the fellows in diabetes.”

Efforts have been made to educate whole offices and established physicians using in-service training, chart audits, and other methods with mixed results. To bring about change at this level, “we need to look at reimbursement,” says Marrero.

“It’s very tough to change doctors who have been out many years,” adds Hiss, who likewise thinks changing how diabetes care is reimbursed may bring about improvements in care. He thinks translation of diabetes findings also would be improved if the U.S. healthcare system could be reorganized to provide a “chronic disease model” of care for diabetes. Under such a model, care is planned—everything a diabetic patient might need in terms of tests, education, specialist visits is regularly scheduled—and there is a strong emphasis on prevention either of the disease or of its complications. Most medical care is now delivered under an “acute care model,” where treatment is often in response to crises.

“The most effective diabetes care programs address patient, practitioner, and [the health care] system,” says Dr. Charles Clark, director of the DRTC at Regenstrief Health Center in Indianapolis, IN, who recently worked with a Las Vegas-based managed care organization to improve its diabetes care.

With intensive management over a year, the managed care organization was able to make improvements in several areas. For instance, the number of patients in the high-risk category (A1c greater than or equal to 8.0 percent) decreased by 58.3 percent; approximately 97.4 percent of the people in this risk category had a change in their treatment regimen during the study. Among the other successes: more people had their blood pressure checked regularly, and there was a decline in hypertension. There was also a decline in the percentage of patients in the highest risk for coronary heart disease (LDL greater than 130 mg/dl) from 25.4 percent at baseline to 20.2 percent.

“We had patient, physician, and system changes happening,” says Clark, who details the study in the June 2001 issue of *Diabetes Care*. The doctors increased their compliance with the Health Plan Employer Data and Information Set 1999 Diabetes Quality Improvement Project measures, which define how often patients should have dilated eye exams, foot exams, urinary microalbumin measurements, lipid profiles, and A1c tests. Patient risk for cardiovascular disease, nephropathy, and other conditions was

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assessed, and patients and doctors received the assessment reports. Patients attended programs that educated them about their risk status and learned what actions were necessary to prevent problems, and the health team coordinator studied patient records monthly using a computer application to track timing of interventions.

There was a good deal of satisfaction with the Las Vegas program, says Clark. Even one change, like making a printout of risk, made a difference because “the doctors weren’t wasting time convincing patients there was a problem—they could see there was one. Patients also felt that the physicians were paying attention.” Clark hopes to try a large-scale version of this

study in the future.

One of the significant questions is how could changes like those that occurred in the Las Vegas study be carried over to solo practitioners, says Clark. When doctors at a rural practice in Clinton County, IN, asked Clark and his colleagues for help, the practice managed improvement for about six months. After a year, most of the improvements had disappeared, possibly because there hadn’t been a strong patient education component.

“If any one piece falls out, it doesn’t work. We need activated patients, a practitioner with guidelines, and systems that educate patients and support practitioners,” says Clark.

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### **WORKING IN THE COMMUNITY**

Diabetes is more common in African Americans than whites, and “in our area, African Americans are more likely to have diabetes than African Americans elsewhere,” says James Pichert, director of the Clinical Outcome and Behavioral Sciences (COBS) Core at Vanderbilt University’s DRTC in Nashville, TN. “It may be because of cultural factors. It may be that the gene pool for diabetes is deeper here.” Whatever the reason, Vanderbilt’s DRTC researchers are especially interested in learning what it will take to eliminate the racial disparities in the prevalence of diabetes in their region and elsewhere.

There is no textbook on how to change a community’s attitudes toward diabetes, says Pichert. But there are ways that researchers can be more successful when they work with communities.

An educational psychologist by training, Pichert was hired to do research on how to promote diabetes knowledge. To work, any educational strategies that researchers develop have to be appropriate to the community and practical enough to be used.

To come up with good strategies, Pichert thinks researchers need to do their homework and read every-

thing they can about the community in which they hope to work; they need to make friends who are well connected in the community, and they need to keep showing up. Judge Mattielyn Williams, an administrative law judge for the state of Tennessee and an advocate for better diabetes care in African American communities, is an important connection for the researchers. “She took it upon herself to help us at Vanderbilt get plugged in,” says Pichert.

Williams accompanied Pichert and colleagues to meetings with ministers; when someone needed a health speaker, she’d often team up with Pichert; when he gave talks, she’d debrief him and let him know when his message was off the mark. She kept sending Pichert back into the community, even when he felt as though he had embarrassed himself. “She told me, ‘you have to go back. Only if you keep showing up, will people begin to trust you.’”

For meaningful health changes to occur in a community, there has to be a coalition that backs the idea; attention has to be given to the supports and barriers to the changes, and behavioral support systems have to be put in place to keep positive changes going, says David Schlundt. He directs the DRTC’s COBS Core and Vanderbilt’s Behavioral Health Disparities Core,

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which is based at Nashville's Meharry Medical College, the training ground for many of the country's African American physicians and dentists.

The Vanderbilt researchers began building ties in the community in the early 1990s. By 1997, a coalition had formed with the aim of reducing health disparities. The Nashville Disparities Coalition now includes Matthew Walker Comprehensive Health Center, Meharry Medical College, Fisk University, Tennessee State University, the county hospital, local and state health departments, the Nashville Branch NAACP Health Community, ministers, concerned citizens, and the Vanderbilt DRTC. "It had its seeds in the American Diabetes Association African American Initiative and came to a head with NIH's emphasis on health disparities," says Pichert.

The coalition has made possible a series of research collaborations between Schlundt and Meharry colleagues on African American women's eating habits and a project funded with a Centers for Disease Control and Prevention REACH (Racial and Ethnic Approaches to Community Health) grant. The grant to the coalition has Matthew Walker Health Center as the lead agency; the DRTC has a subcontract with the center to provide evaluation of programs, says Schlundt. He says that Vanderbilt's social science expertise, built with DRTC funding, has been one of its primary contributions to the coalition. "We've also supported the coalition in community building and in obtaining resources."

The members of the coalition have worked especially hard to promote the community's readiness to change. Under the direction of Michelle Marrs, CEO of the Walker Health Center, and her colleague Linda McClellan, community-based REACH teams of health educators and outreach workers are making people aware of health disparities in their community by using data provided by Nashville's Metropolitan Health Department. Public service announcements, surveys in schools, cookbooks, referral services, and stories in community newspapers have raised awareness. A popular local disc jockey talks about his diabetes on the air,

and the REACH teams make presentations at community events and work with a local managed care group to promote better screening and with local transportation providers to get people to services, says Pichert.

When Schlundt and the REACH teams looked at barriers to treating or preventing diabetes, they tackled problems in pieces. For instance, "we want to promote exercise, but focus group participants told us they don't go out because of problems like broken street lights or mean dogs on the street. We are beginning to work with the city to improve street conditions."

Smoking is bad enough for health, but it's deadly when combined with diabetes, says Pichert. To reduce smoking among juveniles, REACH team members are working to limit the practice of selling loose cigarettes. In some poor communities, shopkeepers sell cigarettes one at a time, making them affordable to children. "The goal is to let store owners know that it is a violation to sell to children. If local people would tell the police about it, we can encourage an officer to swing by and give warnings," says Pichert. The local police chief, who is African American and interested in community policing, supports the effort.

When it comes to creating behavioral support systems, the REACH teams have worked with local shops to offer "REACH sandwiches," healthy, lower fat choices. They've worked with the Interdenominational Ministers' Fellowship to identify pastors interested in health. The goal is to help pastors and their churches' health committees or nurses' guilds to sponsor activities like cooking and exercise classes. Because the churches have standing in the community, people are more likely to go to their programs.

Only the people in a community can tell researchers about issues—like the loose cigarette sales—that are specific to their neighborhoods, says Pichert. He says the coalition partners believe that the researchers' role is to help empower the community to identify those problems, set priorities, find potential solutions, and evaluate results, but "not tell our colleagues and neighbors what to do." Once the community decides what its

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health priorities are, researchers can help them understand the scientific basis for necessary changes and assess programs once they come into play. “We can then feed the data back to the community, so they can decide what needs to be done next,” says Pichert.

On a personal note, Pichert sees work in this field as “an opportunity to make a generational difference.” When the disease strikes older African American women many people feel the impact, says Pichert. “One of my favorite research assistants had to drop out of Vanderbilt and go home because his diabetic grandmother had a stroke and could no longer care for his grandfather.”

“We’d like to see the grandmothers, who are the glue of the community, have far, far fewer diabetes-related strokes and amputations,” says Pichert.

“It will be several years before we can even hope to see if what we are doing has an impact on major health outcomes like stroke,” adds Schlundt. “We hope to see changes in behavior first, but even that will take a couple of years.”

Because there is no one formula to change a community, the DRTCs continue to search for methods that will work at the local level.